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ABSTRACT

This fact sheet uses a question-and-answer format to summarize what is known about Reye's Syndrome, a disease probably caused by ingestion of salicylate, which affects all organs of the body but especially the liver and brain, often resulting in neurological abnormalities and mental retardation. The following topics on the subject are covered: what Reye's Syndrome is; whether taking aspirin, especially by children, causes Reye's Syndrome; the incidence of Reye's Syndrome (approximately one per one million individuals in the United States currently); warning signs of Reye's Syndrome; the importance of early diagnosis; treatment of Reye's Syndrome; and sources of additional information. (DB)

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Q&A

# Reye's Syndrome

by Leigh Ann Reynolds, M.S.S.W., M.P.A.

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Q&A

# Reye's Syndrome

by Leigh Ann Reynolds, M.S.S.W., M.P.A.

## What is Reye's syndrome?

Reye's (pronounced "rye") syndrome is a disease which is believed to be caused by the ingestion of medicines (such as aspirin) that contain salicylate (pronounced "sa•LISS•a•late") that affects all organs of the body, but affects the liver and brain most lethally. It occurs when abnormal accumulations of fat develop in the liver and other organs of the body, along with a severe increase of pressure in the brain. It affects mostly children and teenagers and appears soon after flu-like infection or chicken pox. Reye's syndrome occurs most frequently during the months of January, February and March when influenza is most common, although cases have been reported throughout the year.

Reports of the syndrome appeared as early as 1929, but it wasn't until 1963 that the symptoms were first recognized as a distinct disease by R. Douglas Reye, M.D., an Australian pathologist. Dr. Reye suspected that a drug or poison (later identified as aspirin) triggered the disease's development, but there was no proof of such a substance in the homes of the children who acquired the illness, nor did autopsies reveal the presence of any such substance ingested by the child.

## Can taking aspirin cause Reye's syndrome?

Although the exact cause of this rare syndrome remains unknown, research has shown that the ingestion of aspirin during and after a viral illness, such as chicken pox, flu or other respiratory tract illness, significantly increases the chance of Reye's syndrome. One study found that 90 percent of patients with Reye's syndrome had taken aspirin before or during a viral illness. Most of those affected (96 percent) took medications containing aspirin on or before the third day of illness. Another study found that children with the syndrome were 35 times more likely to have used aspirin than those who did not take any aspirin (Huritz, 1988; Huritz, et.al., 1987). Due to these findings, ***people (especially children) with viral illnesses are encouraged not to use aspirin or any medications containing aspirin since it could cause Reye's syndrome.***

By the 1980s, reports of the danger associated with aspirin use were publicized, spurring a marked decrease in its use among children with viral illnesses. This decrease in aspirin use was accompanied by a decline in reported cases of Reye's syndrome. The decline has been most dramatic in those 5 to 10 years of age (Hurwitz, 1988). In 1988, the Food and Drug Administration (FDA) required aspirin manufacturers to add warnings to product labels about the possible association between Reye's syndrome and aspirin. The label, which is still being used today, reads: *Children and teenagers should not use this medicine for chicken pox or flu symptoms before a doctor is consulted about Reye's syndrome, a rare but serious illness reported to be associated with aspirin* (Zamula, 1990).

**QUICK FACTS**

**Condition:** *Reye's syndrome (pronounced rye); a disorder that affects all organs of the body, but most lethally affects the liver and brain*

**Link to Mental Retardation:** *Children who survive are often left with neurological abnormalities and mental retardation*

**Primarily affects:** *Children and teenagers*

**Symptoms:** *Stage 1: Continuous vomiting, nausea, loss of energy, signs of brain disorder, such as drowsiness, listlessness and staring*
*Stage 2: Irritability, aggressive behavior, delirium, disorientation, slurred speech, convulsions, may not recognize parents, possible comatose*

**Incidence:** *Approximately one per one million individuals is affected*

**Cause:** *Unknown, but strongly associated with aspirin use taken during or following viral illness, such as chicken pox and flu*

**Treatment:** *No cure; treatment requires intensive hospital care focusing on reducing swelling of the brain*

**Contact for more information:** *The National Reye's Syndrome Foundation at 1-800-233-7393 (http://www.bright.net/~reyessyn)*

Most people are surprised to discover that giving over the counter medication during or after a time of illness can bring serious harm to children. However, aspirin contains salicylate which can accumulate within a child's body, resulting in Reye's syndrome. Many over the counter medications contain salicylates, including Pepto Bismol, Excedrin, Anacin, Bufferin, Coricidin, Triaminicin, Alka-Seltzer, Aspergum and Dristan tablets. Due to the danger associated with taking aspirin, doctors recommend that children be given medication containing acetaminophen (pronounced "a•SEE•ta•men•o•fen") which is found in non-aspirin drugs such as Tylenol and Tempra. Acetaminophen is safer because it does not accumulate in the body with repeated doses as aspirin does. Both are equally effective in reducing fever and pain (Stehlin, 1987).

## What is the incidence of Reye's syndrome?

Reye's syndrome is rare, affecting approximately one per one million individuals in the population. However, the number of known cases (along with milder cases) has increased as awareness of the syndrome has grown. In 1977, there were over 500 cases found by the Centers for Disease Control (CDC), but by 1985 the number of cases decreased to 93. The National Reye's Syndrome Foundation continues to track the number of cases, documenting approximately 50 per year. Reye's syndrome has been found to affect all ages, from a four day old newborn to a 59 year old



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individual. However, more than 90 percent of those affected are under age 15 (Zamula, 1990).

Research has found that as the incidence of Reye's syndrome decreased, patients with clinical features similar to those of Reye's syndrome were more likely to be due to inborn errors of metabolism (Rowe, Valle & Brusilow, 1988). Inborn errors of metabolism are disorders of metabolism that occur when cells are unable to produce proteins or enzymes which are needed to change certain chemicals into others. Some of the clinical and laboratory features of the syndrome can mimic those disorders found in metabolic disorders, making it difficult to establish an exact diagnosis.

## What are the warning signs?

Reye's syndrome should be suspected if a pattern of certain symptoms appears either during or after a viral illness. Symptoms often occur AFTER an illness, such as the flu or chicken pox. Other viruses associated with Reye's syndrome include: Mumps, Rubella (German measles), Rubeola (measles), Polio, Epstein-Barr, Herpes Complex, Cytomegalovirus, Coxsackie A and B and Adenovirus 2 and 3 (Stehlin, 1987). Although many diseases have symptoms in common, Reye's syndrome can be identified when symptoms (which occur in two stages) are carefully noted so that an observable pattern emerges.

Reye's syndrome can occur several days (1-14 days) after a viral infection and generally progresses through two stages. The first stage includes persistent or continuous vomiting, severe tiredness, belligerence due to illness (moodiness), nausea and loss of energy. The second stage follows with personality changes, bizarre mental and physical behavior (such as confusion, restlessness and irrational behavior), and lethargy or inactivity of the senses sometimes to the point of comatose and convulsions. Vomiting is often the first sign of Reye's syndrome, except for children under two who may have diarrhea or hyperventilate. The duration varies according to the severity of the disease. Symptoms can range from mild to serious, possibly progressing to death. However, its progression can also stop at any stage allowing for full recovery in five to ten days.

## Why is early diagnosis important?

Early diagnosis is vital. Unless the individual with Reye's syndrome is properly diagnosed and treated successfully, death is common and may occur in only a few days. The earlier the diagnosis and treatment, the better the chance of survival. There is a 90 percent chance of recovery for those diagnosed early and only a 10 percent chance of recovery for those diagnosed late. The fatality rate among those with Reye's syndrome is 52 percent (National Reye's Syndrome Foundation, 1996).

If the child does survive there can be lasting effects, depending on the severity of the swelling of the brain. These children often have neurological abnormalities resulting in mental retardation. While some have slight to severe brain damage, others appear to recover completely. Psychological and neuropsychological testing should be conducted to determine the extent of impairment that was sustained as a result of the syndrome.

Due to the speed at which the illness can progress, it is important to be informed of the warning signs associated with this condition in order to identify its existence as soon as possible. This can be difficult since doctors are often unfamiliar with this disorder due to its rarity. Medical staff in emergency rooms sometimes misdiagnose Reye's syndrome as encephalitis, meningitis, diabetes, poisoning, mental illness or drug abuse, since the incidence of the syndrome is low, and many people are still unaware of its existence. Writing down the child's specific symptoms (including the exact description and frequency of behaviors) and requesting the doctor's careful documentation of the symptoms within the child's medical file is crucial in obtaining a more timely and accurate diagnosis.

## How is Reye's syndrome treated?

Although there is no cure for Reye's syndrome, treatment can help reduce the effects caused by the disorder. Treatment is typically provided in an intensive care unit at a hospital. Children affected by this disorder require intensive monitoring of their fluids, electrolytes, blood gas status and nutrition. The amount of pressure of the fluids within the skull, as well as blood pressure, is closely monitored. Barbiturates and other drugs may be given to reduce this pressure and cool body temperature. Insulin is often given to increase glucose metabolism, corticosteroids to reduce brain swelling and diuretics to increase fluid loss. Patients are not given any food by mouth, but are fed intravenously. A breathing machine or respirator may be needed if the child begins having greater difficulty in breathing. The outcome of each case depends, in large part, on the amount of swelling that occurred in the brain (Kids Health Organization, 1996).

## Where can I get more information about Reye's syndrome?

The National Reye's Syndrome Foundation, formed in 1974 by parents of affected children, can provide educational materials, telephone counseling, information on support groups and other assistance. The foundation has 120 volunteer affiliates in 43 states. To find out if there is a local chapter near you, contact the National Reye's Syndrome Foundation (426 North Lewis Street, Bryan, OH 43506) at 1-800-233-7393.

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